



2014

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Recommended Citation

Staniszewska, Sophie and Churchill, Neil (2014) "Patients' experiences in the UK: Future strategic directions," *Patient Experience Journal*: Vol. 1 : Iss. 1 , Article 18.

DOI: [10.35680/2372-0247.1017](https://doi.org/10.35680/2372-0247.1017)

Available at: <https://pxjournal.org/journal/vol1/iss1/18>

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Patients' experiences in the UK: Future strategic directions

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Abstract

Over the last decade policy has emphasised the importance of a good patient experience as a cornerstone of high quality health and social care in the UK, with many initiatives attempting to develop patient-centred practice. More recently, the Francis Inquiry has addressed the significant failings in care identified at Mid Staffordshire NHS Foundation Trust in England and has been pivotal in raising the importance of patient experience.¹ The Francis report made 290 recommendations, with many emphasizing the importance of patient experience through their focus on specific ways in which the quality of experiences can be enhanced, for example, by improving support for compassionate, caring and committed care, achieved through stronger healthcare leadership. The linkages between experience, patient safety and clinical effectiveness have also been emphasized more recently.² For the first time commissioners in England are working together to set a national level of ambition to improve experiences of care.³ Yet while policy has attempted to place patient experiences at the heart of care, significant challenges still remain before patient experience is fully integrated conceptually and organisationally. We review some of the key challenges in relation to research and consider ways forward.

Keywords

Patient experience, patient-based evidence, health policy, implementation, patient and public involvement

In this short paper we consider the current state of patient experience research, practice and policy in the UK context and reflect on some of the key challenges for the next decade

Raising the status of patient experience as a form of evidence

Patients' experiences have been collected in a range of ways in the UK, with many NHS organisations routinely surveying patients' views of care.⁴ While significant data collection has taken place nationally, it has not always been clear whether health care organisations have viewed the creation of a good patient experience as core business, of equal status to clinical effectiveness and economic efficiency. Nor has experience data always been viewed alongside other sources of data on quality. Indeed, we might argue that in the past patient experience was tacitly regarded as the 'poor cousin,' regarded as important, but maybe not quite as strategically significant as clinical effectiveness and economic efficiency.

While the Francis Report has been pivotal nationally and locally in creating a renewed focus on patient experiences, there still remains a need to strengthen and consolidate the importance of experience by raising its status, so it remains a key strategic priority in the future. We argue that experience is a vital component of care and that it is time for patient experience to sit alongside, and be integrated

with, clinical and economic considerations. Furthermore, experience provides a vital insight in aspects of care that creates value for patients, which must be a fundamental part of any service provision or service change. The eminent epidemiologist Richard Doll captured this very well, when he said "what is the point of providing clinically effective and economically efficient care, if no-one wants it".⁵

However, raising and securing the status of patient experience poses challenges for organisational cultures, norms, structures, systems, attitudes and ways of working. The direct links between staff experience and patient experience, underscored by organisational culture, are now well established.⁶ and yet addressing issues like supporting staff, appraisal and bullying in some organisations has proved challenging.⁷ Health care is a complex area of activity and we need to consider a range of approaches to support the conditions required to consistently deliver a patient-centred service. One way forward might be move from a position where patient experiences is seen as information or data which is useful, but not always essential, to a consideration of experiences as a vital form of evidence. Within this conceptualisation, patient experience could be seen as part of a broader concept previously termed *patient-based evidence*^{8,9} which reflects the patient's cognitive (what happened) and affective (how did I feel about it) evaluations of key dimensions of their health and social care experience, captured as qualitative or

quantitative data. In the same way as Sackett and colleagues¹⁰ conceptualised evidence as vital for effective healthcare, we need to re-conceptualise patient experience as a key part of Sackett's vital evidence, serving a specific and particular purpose by complementing and adding to clinical and economic data. The POPPY study provides an example of how re-conceptualising experience as a vital form of evidence might work. We examined parental experiences of neonatal care and drew on a range of data, including a large qualitative study of parents' experiences, a systematic review of interventions that aimed to enhance information, communication and support and a neonatal unit survey of current practice. Working collaboratively with our parents, we developed a model of care, which offers practitioners clear guidance on what forms of practice will enable a good parent experience.¹¹ While many already see experiences as evidence, our argument is that it should be more widely accepted as the norm within the provision, commissioning and evaluation of care.

Conceptualising experiences as evidence would mean health care organisations move towards an evidence-based approach in relation to the effectiveness, acceptability and appropriateness of services. Organisations could challenge themselves by asking 'what evidence exists to support our current practice and the extent to which it generates a good patient experience.'

Creating this demand for patient-based evidence to underpin the provision of health care would mean that those organisations tasked with the synthesis of evidence and the provision of guidance should consider including patient experience in their conceptualisation of vital evidence. Important progress has been made, with organisations such as NICE publishing generic guidance for enabling a good patient experience^{12,13}. NICE has recently published an update of its Patient Experiences Guidance¹⁴, an example of how the patient experiences evidence base can be drawn on to inform practice. The Cochrane Consumers and Communication Group have also published a wide range of relevant reviews to inform practice.¹⁵ While these and other publications and initiatives have been important, there is still a demand for reviews of condition-specific areas and particular contexts. One possibility would be a specialist Centre, which could undertake relevant syntheses and provide guidance or the extension of the work of existing organisations.

The need for a robust evidence base

Conceptualising patient experiences as a vital form of evidence inevitably leads to the question of the robustness of the patient experience evidence base. As the 'poor cousin,' patient experience has suffered both conceptually and methodologically, with less development when compared to the clinical and economic forms of evidence. While fields such as patient-reported outcome measures

(PROMS) have drawn on robust methodologies for development and testing of instruments that aim to measure quality of life¹⁶, the use of theoretical frameworks, robust development and thorough evaluation has been more variable in patient experience, although the last decade has seen a significant expansion of experiences studies with a focus on evaluating reliability and validity of instruments¹⁷. In the UK the Picker Institute and others have developed robust questionnaires for use at national level⁴, but many local health care organisations still collect their own data using their own tools, in an attempt to understand local issues. The NHS in England has invested in the Friends and Family Test¹⁸, an experimental measure of experience that is still in its first year of national implementation, whose primary value appears to be in the text feedback left by individual patients. However, if we are to conceptualise experiences as evidence, we need to encourage the philosophy of research rigour. Whether it is developing valid and reliable instruments, or using well-validated instruments, or drawing on high quality experiences studies to inform practice, we need to generate high quality evidence which can be used to guide practice. Organisations need to challenge themselves by asking 'how robust are our methods for acquiring patient experiences data?' Commissioners and providers of NHS care may need to develop their capacity and capability to synthesise and interpret qualitative and quantitative patient-based evidence in their decision-making.

Implementation

While evidence to underpin effective practice is important, there is an increasing recognition that evidence is not enough to change practice, and there is a need to consider how best to implement patient-based evidence. While implementation as a field of research has progressed in the last decade, relatively few studies have focused specifically on the best ways of implementing interventions that enhance a good patient experience. Conceptual frameworks such as PARIHS, which considers the key dimensions of evidence, context and facilitation, have been important in developing an understanding of the key aspects of implementation.^{19,20} These dimensions relate very well to patient experience and could be very useful when planning the implementation of complex interventions such as the NICE Patient Experiences Guidance.^{13,21} Experience based co-design has also demonstrated effectiveness in generating change based on patient perspectives and collaboration between patients and staff.²² These are promising beginnings but demonstrate that in addition to developing patient-based evidence to inform practice, we also need to extend our thinking towards studies that explore and identify the most effective forms of implementation, to ensure we embed good practice securely within care.

Patient and public involvement in experiences research

While most patient experiences research has focused on identifying the content and nature of experiences, less emphasis has been placed on developing partnerships with patients, working collaboratively to identify key questions, develop methods and analyse and interpret results. In the UK, the move towards active collaboration with patients and the public in research has developed over the last decade.²³ There is enormous potential in to work with patients and the public in developing a patient experiences research agenda for the future²¹, so the methods are appropriate and the findings have relevance for patients, particularly important in a field whose primary endeavour is to understand the experience of an individual or group. Indeed, with service design needing to respect the culture, values and preferences of diverse patient populations, patient and public involvement is an integral part of any research programme.

Patient leadership

Most initiatives that aim to enhance patient experiences focus on systems or health care professionals. Relatively few have focused on the role of the patient and their contribution to enhancing experiences, through individual activity and collective forms of patient leadership. Organisations such as the Centre for Patient Leadership (CPL) provides learning and support for a new generation of healthcare patient leaders. They state that:

*"Now more than ever, the NHS needs new leaders and innovative solutions. But patients, service users and carers are seen as part of the problem and remain a huge untapped asset. It's time to shift our thinking."*²⁴

Patient leaders in health care practice and in research offer exciting opportunities for partnership in the future, contributing to the creation of patient-based evidence and to its implementation, to ensure patient experiences is firmly embedded as a vital form of evidence, informing the provision of care that is effective, acceptable and appropriate from the patient perspective. They also present health organisations with the challenge of letting go and allowing patients to influence conceptions of quality and definition of priorities. This is a challenge we need to embrace if we are to realise the potential of experience as a form of evidence which can complement safety and clinical outcomes and creates value patients want.

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